

SJLIFE

Post-Visit Survey



Our mailing address is:
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

Toll-free phone number:
1-800-775-2167

e-mail:
SJLIFE@stjude.org

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Please! Do not mark below this line

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box.
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided.

I. Reasons for St. Jude Life Participation:

How important were the following items in your decision to take part in the St. Jude Lifetime Cohort Study?

		Very Important	Important	Neither Important or Unimportant	Unimportant	Very Unimportant
1. To visit St. Jude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. To see the nurses/doctors I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. To see the kids at St. Jude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. To have a thorough medical check-up at St. Jude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. To have a check-up at no cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. To learn about late effects after childhood cancer and ways to stay healthy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. To help others with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. To help St. Jude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. To visit other people/sites in Memphis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. To receive money provided to study participants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Other reasons	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If Other reasons, please specify:

Please! Do not mark below this line

II. Recruiting & Scheduling the SJLIFE Evaluation:

What best describes your experience with the staff who contacted you and arranged your St. Jude Life visit?

1. I received enough information from the first person who called to know if I was interested in taking part in the study.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

2. I had a hard time contacting the right person to talk to about the study after receiving the first telephone message.

- Not Applicable
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

3. Once I agreed to take part in the study, my appointment was scheduled quickly.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

If you had to fly to Memphis for your appointment, please answer the following question.

4. The St. Jude Travel Office did a good job in arranging convenient travel plans for my visit.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Please! Do not mark below this line

III. St. Jude Life Educational Materials

What best describes how you feel about the study brochures and other educational materials given to you before or during your St. Jude Life visit?

- | | Strongly Agree | Agree | Neither Agree/Disagree | Disagree | Strongly Disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. The study brochure(s) I received in the mail provided helpful information | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. The instruction manual I received before my St. Jude Life visit provided information that was easy to understand | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I received the instruction manual in enough time to read it before my St. Jude Life visit | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

The clinical summary of my cancer treatment discussed during my St. Jude Life visit:

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 4. Helped me understand the health problems that could occur after my childhood cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Helped me understand which health screening tests I should have to check for problems that could occur after my childhood cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Helped me understand the health habits I should practice or change to reduce my risk of problems that could occur after my childhood cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

IV. St. Jude Life Health Surveys

Please describe how you feel about the health surveys you were asked to complete before or during your St. Jude Life visit.

- | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. There were too many health surveys to complete before and during the visit | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. It was helpful having the health surveys mailed to my home before the visit | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I had enough time to complete the health surveys given to me after I arrived at St. Jude | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. The health surveys were too long | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. The questions asked in the health surveys addressed health issues of importance to me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I would prefer to answer the health surveys online (by computer) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I would prefer to answer the health surveys by talking with an interviewer over the phone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please! Do not mark below this line

V. St. Jude Life Visit

We would like your opinion about the different parts of the St. Jude Life visit. In each area, please rate your satisfaction with your interactions with the study team or hospital services. We would be interested to know both where you felt we did a good job and where we need to improve.

Research Team

- | | | | | | | |
|---|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| | Very Unsatisfied | | | | | |
| | | Unsatisfied | | | | |
| | | | Neither Satisfied or Unsatisfied | | | |
| | | | | Satisfied | | |
| | | | | | Very Satisfied | |
| 1. During the initial consent process, the research nurse fully explained what would happen during my visit | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. The study consent form fully explained what would happen if I decided to take part in the study | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I was fully informed about the reason for the tests performed during my evaluation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Hospital Services

Please rate how satisfied you were with how you were treated in each hospital service area.

- | | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 4. Patient Services (lodging, fuel reimbursement, flights) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Assessment/Triage (where vital signs were taken and blood drawn) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Functional Assessment (evaluation of strength and balance, walking test, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

If you did not have an appointment in one of the following hospital service areas listed, please mark "Not Applicable".

- | | | | | | | |
|--|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| | Very Unsatisfied | | | | | |
| | | Unsatisfied | | | | |
| | | | Neither Satisfied or Unsatisfied | | | |
| | | | | Satisfied | | |
| | | | | | Very Satisfied | |
| | | | | | | Not Applicable |
| 7. Diagnostic Imaging (X-ray, bone density testing, CT, MRI) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Echo Lab (heart testing) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Pulmonary Lab (lung function testing) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Eye Clinic (vision testing) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Audiology (hearing testing) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Neuropsychological Testing (memory, attention, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Services off St. Jude campus

- | | | | | | | |
|---------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 13. Breast cancer screening | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Colon cancer screening | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Sperm count testing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please! Do not mark below this line

Appointment Schedule, Transportation, and Lodging

16. I did not feel rushed between appointments.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

17. Clear directions were provided to appointment locations on the St. Jude campus.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

18. Clear directions were provided to appointment locations off the St. Jude campus.

- Not Applicable
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

19. Transportation between appointments was provided where needed.

- Not Applicable
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

20. I was satisfied with my accommodations in the Grizzlies House.

- Not Applicable
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Social Worker, Nurse Practitioner & Physician

21. The information I received about steps I could take to stay healthy, based on the results of my tests, was helpful.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

22. The information I received about health risks associated with my cancer and cancer treatment was helpful.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

23. I was instructed about the type of health check-ups I need in the future.

- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

24. The study team helped me find the medical services I needed in my community.

- Not Applicable
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Please! Do not mark below this line

Overall

25. I was satisfied with the amount of time the study team spent with me.

- Very Satisfied
- Satisfied
- Neither Satisfied or Unsatisfied
- Unsatisfied
- Very Unsatisfied

26. Did you have unexpected problems during the evaluation?

- No
- Yes

If so, what were they?

27. Do you have any suggestions for how we can improve?

- No
- Yes

If so, what are they?

Interest in returning for another SJLIFE evaluation:

28. Would you like to continue to receive information about the St. Jude Life study?

- Yes
- No
- Not sure

29. Would you be willing to share your survivor story in a SJLIFE newsletter or on the website?

- Yes
- No
- Not sure

Please! Do not mark below this line

30. Would you be interested in returning for another St. Jude Life visit?

- Yes **→ Please answer the following questions below.**
- No
- Not sure

31. How often would you be willing to return for a St. Jude Life check up?

- Once a year
- Every 2 to 3 years
- Every 5 years
- Other

If Other, please specify:

Interest in taking part in future research studies

	Very Likely	Likely	Not Sure	Unlikely	Very Unlikely
32. I would be willing to return for a study that may affect my own health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I would be willing to return for a study that does not affect my own health, but would help address health care issues of childhood cancer survivors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I would be willing to take part in a study that involves responding to surveys given by mail or telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I would be willing to take part in a study that involves regular online (internet-based) activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. I would be willing to take part in a study that would require me to change my health habits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I would be willing to take part in a study that involves exercising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I would be willing to take part in a study that would involve taking medicines by mouth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I would be willing to take part in a study that would involve taking medicines by shots	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I would be willing to take part in a study that would involve returning periodically to St. Jude over a period of months to years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I would be willing to take part in a study that would involve having health tests done at my home or work by a health agency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

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 Department of Epidemiology
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Thank you!

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